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## article

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# How do young people 'do' family where there is a diagnosis of dementia?

Mel Hall,<sup>1</sup> [melanie.hall@sheffield.ac.uk](mailto:melanie.hall@sheffield.ac.uk)  
University of Sheffield, UK

Pat Sikes, [p.j.sikes@Sheffield.ac.uk](mailto:p.j.sikes@Sheffield.ac.uk)  
University of Sheffield, UK

This article presents data arising from a project that explored 22 children and young people's experiences of having a parent with dementia. A key theme from the interviews highlighted the implications dementia has for the relationship between children and their parents – specifically, how individuals 'do' and display family when their parent's personality and capacity to function as previously has been undermined. The data illustrate how these young people experience disruptions to existing family practices, and how they perpetuate a relationship with their parent in the face of dementia. It also indicates that these changes in practices – the disruption and acquired significance – contribute to children's reconceptualisation of their relationship with their parent. This article seeks to add to the literature on family practices (Morgan, 2011) and display (Finch, 2007) by using the experience of dementia to illustrate the importance of family practices when a family experiences 'crisis'.

**key words** dementia • family practices • children and young people • biographical research

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## Background

Changes in life expectancy, medical knowledge and diagnostic procedures mean more dementia diagnoses, with figures anticipated to double from 850,000 in 2014 to 2,092,945 in 2051 (Alzheimer's Society, 2015). The incidence of dementia increases from 1 in 100 in those aged 65–69, and rises to 1 in 6 for within those over 80. However, diagnoses of young onset dementia (YOD), occurring before the age of 65, are also increasing. Current figures suggest that, in the UK, 42,325 people have a variant of YOD. Demographic changes such as later childbirth, increased childbearing ages and more people having second and subsequent families mean more children will likely have a parent with the disease. The limited evidence suggests that parental dementia in families with children can lead to significant social and psychological upset, damage, tension, hardship and family break-up (Luscombe et al, 1998; Allen

et al, 2009; Harris and Keady, 2009; Svanberg et al, 2010, 2011; Gelman and Greer, 2011; Hutchinson et al, 2014; Millenaar et al, 2014).

A review of the literature revealed a lack of direct research *with* young people experiencing parental dementia, and highlighted a need for further work in the this area (Roach et al, 2009; Green and Kleissen, 2013). Our study sought to address this gap by exploring the perceptions and experiences of children and young people, applying narrative and auto/biographical approaches to elicit their accounts.

Dementia affects cognitive skills, has physical manifestations and has an impact on an individual's personality, including social withdrawal, lack of empathy, increased temper and loss of interests (NHS, 2015), experienced long before a definitive diagnosis is reached. Such symptoms, coupled with caring needs and altered family roles, mean that dementia has significant implications for familial relationships. This article outlines our findings to consider some of these implications, beginning with a definition of 'family'.

## Theoretical underpinning

Traditional Western constructions equate the family with a heterosexual married couple and their children who perform sexual, reproductive, socialisation and economic functions. It has been considered the lynchpin of society, with social trends such as increases in divorce, lone parenthood, increasing acceptance of homosexuality and the feminisation of the workforce being perceived as threats to 'the family' as a static entity, prompting concerns of 'crisis' (Morgan, 1996). Theorists have countered this argument by shifting the focus from the structural and functional aspects of 'the family' and encouraging a relational and inclusionary approach (Morgan, 1996, 2011). Such a 'family practices' approach understands and theorises family as something that we 'do'.

Thus 'family practices' describe the 'often little fragments of daily life which are part of the normal taken-for-granted existence of practitioners. Their significance derives from their location in wider systems of meaning' (Morgan, 1996: 190). Emerging from this concept is 'family display', which highlights that not only are family activities 'done', they are also *seen to be done* (Finch, 2007). Display helps families demonstrate to members and to others that they are 'doing' family and reinforcing their relationships to one another. As Finch puts it, 'this is my family and it works' (2007: 73). A view of family 'which refers to the sharing of resources, caring, responsibilities and obligations' (Smart and Silva, 1999: 7) incorporates fluidity and facilitates acknowledgement of changes throughout the life course as identities evolve (Hockey and James, 2002).

Historically and culturally, children have come to embody the family, not as social actors in their own right, but as dependents. Scholars of childhood studies, however, have recognised that children are active social agents whose 'voices' should be directly sought. Davies (2015) argues that this is imperative in the context of the family and with regard to other important social relationships for understanding the individual and the family.

A family practices approach encapsulates this holistic, socially located perspective that has been applied to explore families whose practices are altered as a result of parental YOD, where expectations of what different family roles and positions entail have been disrupted. Such expectations may be specific to a particular family, arising out of its unique history and circumstances, while others are located in broader

social and cultural contexts. Structural changes retain young people in education, while precarious employment, rises in the cost of living and reduced state support render many young people financially dependent on their parents and delay them starting their own families. Increasing numbers are remaining in the family home throughout their late twenties and into their thirties (ONS, 2014). Arnett (2004) terms this 'emergent adulthood', and this delayed independence has been considered problematic (Apter, 2001). This changes expectations of parents and children's roles across the life course.

By the same token, children adopting responsibilities 'prematurely' is also problematic, illustrating tensions around their roles. Research with young carers illustrates how children 'do' family in, what are traditionally regarded as, difficult circumstances. It highlights adverse outcomes affecting educational progress, career choice, social and emotional development and mental and physical health (Aldridge, 2008; NCB, 2016). However, constructions of young carers have been subject to critique (Eldén, 2015), and it has been argued that childhood and caring need not be constructed as mutually exclusive. Instead, Eldén (2015) identified an 'ordinary complexity of care' in families that represents everyday life for some, rather than a deviation from the norm. The reality is that all relationships are interdependent and reciprocal (Wihstutz, 2011). Excess emphasis on a one-directional flow of care inherently problematises reciprocity and increases children's vulnerability, causing them to hide or deny their roles. The problem is not parents who are ill or disabled requiring care from children per se, but inadequate support systems (Aldridge, 2008; NCB, 2016). While the participants in our study resisted the carer identity (NCB, 2016), such literature demonstrates children and young people's participation in family practices and display, which, we will illustrate, happens where parental dementia occurs.

## The study

### *Data collection*

An auto/biographical approach elicited stories 'to understand the individual life within its social context' (Roberts, 2002: 3), including reflections on past and current experiences and speculation on the future. The social sciences have witnessed a narrative, biographical or auto/biographical 'turn' (Riessman, 2008), particularly among researchers concerned with social justice issues seeking to give voice to hidden and 'silenced lives' (McLaughlin and Tierney, 1993; Goodson and Sikes, 2001; Plummer, 2001). Such approaches were appropriate given that we sought to explore the experiences of young people who are in a minority, whose experiences violate the normal order of life events, and who are affected by a stigmatising (Goffman, 1963) and identity-spoiling condition (Werner et al, 2010).

In-depth interviews were carried out with 22 participants with experience of having a parent with dementia. The broad age range facilitated exploration of how education and early adult life choices might be affected by parental dementia. Our initial upper age limit was 25, but we felt ethically obliged to include volunteers over this age who wished to share their stories that covered childhood and/or adolescence.

Participation involved up to three interviews over a 12-month period, each lasting between 45 minutes and two hours. Three sibling pairings were interviewed, one jointly, two separately. With those aged 6–9, activities such as 'my day', timelines

and family trees yielded biographical accounts. The iterative approach enhanced familiarity and trust and, most importantly, captured developments in the parents' condition, such as a definitive diagnosis, a decline in the parents' condition, moving into residential care and bereavement. The nature of the illness meant that we did not know what changes would occur over the project's lifespan. The data collected was primarily about children and young people's current lives, although most included some retrospective reflections. Two of the older participants' parents had died less than a year before their involvement in the study, and we consider grief to be an important part of the young people's accounts. One participant (Grace, 31) provided a retrospective account of being aged 11–21 and having a parent with dementia, her mother having died.

The study was advertised across social media (Twitter and Facebook) and by the Alzheimer's Society and Young Dementia UK. Other participants came to the project having been searching for support online. Outlets directly aimed at young carers were avoided in order to reach those who didn't identify as carers (and indeed, several participants explicitly rejected the 'carer' label). Ethical approval was granted by the University of Sheffield.

Participants were experiencing parental dementia at varying stages: preliminary stages of formal diagnosis, relatively recent diagnoses, several years post-diagnosis (although in hindsight, participants felt they had been living with dementia-related behaviours for significantly longer), and bereaved by dementia. Further details are provided in Table 1.

Analysis took a thematic approach whereby themes were drawn out of narratives in a fashion that retains the story in its entirety (Riessman, 2008).

## **Dementia and 'doing' family**

Narratives of having a parent with dementia illustrated how parent–child relationships and 'doing' family were affected. Using the family practices lens to view these accounts highlighted the quotidian yet significant impacts of dementia and its challenges. Interviews began with the invitation 'Tell me your story' and participants typically talked about how their family had changed, starting with an anecdote about 'strange' or 'unusual' behaviour which denoted the fact that something was 'wrong'. Their usual ways of being a family were interrupted. Participants described the disruption to their relationship with their parent, for example, the things their parent could no longer do for them or that they could no longer do together, and new activities undertaken. Narratives revealed the ways in which children and young people continued to practice and display family: how they spent their time together and the things they would do. Furthermore, these accounts suggest how children and young people 'reconceptualise' their relationship with their parent. These themes will now be explored.

Table 1: Overview of participants (names anonymised)

| Participant | Gender | Age | Parent | Diagnosis (if known)                                     | Estimated years of dementia*                              | Family configuration                                 | Living arrangements   | Current activities       |
|-------------|--------|-----|--------|--|---|--|-----------------------|--------------------------|
| Sheena      | Female | 26  | Dad    | Dementia with Lewy's Bodies                              | 8, deceased during the research                           | Youngest of three siblings                           | Away                  | Employed                 |
| Alex        | Male   | 24  | Dad    | Frontal lobe dementia                                    | 4   | Siblings   | Away                  | Employed                 |
| Anna        | Female | 30  |        |  |   |  | Away                  | Employed                 |
| Lily        | Female | 24  | Mum    | Early onset dementia (EOD)                               | 2   | Only child; divorced parents                         | Away                  | Employed                 |
| Evie        | Female | 17  | Dad    | Fronto temporal dementia (FTD)                           | 5   | Only child   | Father in a care home | Education                |
| Elizabeth   | Female | 28  | Mum    | EOD  | 6   | Youngest of three siblings                           | Away                  | Employed                 |
| Madison     | Female | 23  | Mum    | Posterior cortical atrophy                               | 5   | Only child; divorced parents                         | Away                  | Undergraduate university |
| Gabrielle   | Female | 23  | Dad    | Vascular dementia; deceased 8 years ago (cancer-related) | 1   | Parents divorced. Half sister from her father's side | N/A                   | Employed                 |
| Rachael     | Female | 24  | Dad    | EOD  | 2   | Oldest of two siblings                               | Away                  | Employed                 |
| Bethany     | Female | 21  | Mum    | FTD  | 6<br>Deceased 1 year ago                                  | Youngest of two siblings                             | N/A                   | Postgraduate education   |
| Grace       | Female | 31  | Mum    | EOD  | 10 (when aged 11–21)<br>Mum passed away when Grace was 21 | Only child   | N/A                   | Employed                 |

Table 1: continued

| Participant | Gender | Age | Parent | Diagnosis (if known) | Estimated years of dementia*       | Family configuration   | Living arrangements                       | Current activities     |
|-------------|--------|-----|--------|----------------------|------------------------------------|--|---|------------------------|
| Colin       | Male   | 21  | Mum    | EOD                  | 3                                  | Youngest of five children. Two siblings are his mother's from a previous marriage; two from his father's | Lives away                                | Postgraduate education |
| Jade        | Female | 16  | Dad    | FTD                  | 1                                  | Jade and Amy are sisters, although Jade is adopted. Amy has a young daughter                             | Home                                      | Education              |
| Amy         | Female | 24  |        |                      |                                    |  |   | Employed               |
| Austin      | Male   | 8   | Dad    | FTD                  | 4                                  | Austin has two siblings from his mother's previous marriage so does not share the same father            | Home                                      | Education              |
| Ava         | Female | 22  | Mum    | FTD                  | 2                                  | Oldest of two siblings   | Home                                      | Postgraduate education |
| Holly       | Female | 21  | Dad    | FTD                  | 4<br>Deceased less than six months | Oldest of two siblings   | Away                                      | Employed               |
| Rhian       | Female | 24  | Mum    | EOD                  | 5                                  | Youngest of two siblings   | Lives at home with parents                | Employed               |
| Harriet     | Female | 17  | Dad    | Vascular dementia    | 1                                  | Only child; divorced parents   | Lives with her boyfriend, near her father | Education              |
| Nathan      | Male   | 22  | Dad    | FTD                  | 1                                  | Youngest of two siblings   | Lives away at university                  | Education              |
| Alicia      | Female | 8   | Dad    | EOD                  | 1                                  | Siblings   | Home                                      | Education              |
| Bryony      | Female | 6   |        |                      |                                    |  |   |                        |

### *Disruption to existing practices*

Participants' 'normal' approaches to 'doing' and displaying family had been undermined, with ways of spending time together, such as days out and holidays, ceasing. Some had a parent who had ceased to communicate with or recognise them. For others, some level of conversation occurred but generally regarding their parents' interests because they appeared to have little interest in what their child had to say. Some had a parent whose dementia rendered them angry and violent – sometimes towards them. Several of the participants felt that they had 'lost' their parent and contemplated future lost elements of family display: a mum absent from wedding dress shopping with a daughter, or a dad who is missing at graduation, or who maybe could attend, but would be unaware of what was happening.

### *Continuities*

Narratives highlighted practices whereby relationships were maintained. Managing the dementia and its associated behaviours appeared to be especially significant, for example, tending to their parent's emotional and practical needs. Observing the significance of small, previously taken for granted, interactions enabled some participants to 'feel' a connection to their parents, such as when their parent used their child's name or said "I love you", everyday occurrences that had become rare and significant because of dementia. Existing practices had been disrupted while new or amended ways of doing family appeared. The onus was placed on the child, rather than on the parent or on being equally shared, to ensure they were able to relate to one another, emphasising young people's agency in the relationship.

### *Reconceptualisation of relationships*

For some participants, making sense of the loss and other changes required a reconceptualisation of the relationship with their parent. While some practices facilitated 'doing' family in spite of the disruption, the nature of the relationship had altered. Some termed this 'role reversal', a concept that has previously been contested (Seltzer, 1990), and saw their parent become childlike to them, in terms of needing care. Of course, such changes in family roles over the life course are anticipated, but parental YOD brings them to an earlier stage of the parent-child relationship than might be expected (Hockey and James, 2002). Others talked in terms of two personas: the well parent and the ill parent.

We will now use three case studies to illustrate disruption, continuity and reconceptualisation of family practices and display.

### **Evie**

Evie, 17, is an only child who lives with her mother, following her father's move to residential care. She described a close relationship prior to the onset of her father's frontotemporal dementia, identifying as a 'daddy's girl'. She believed the dementia began when she was about 11, and described the decline as rapid. Her father doesn't recognise her and is incontinent, which she finds difficult. Evie recounted the journey to diagnosis and its disruptive elements.



## *Disruption*

Evie described the impact the dementia had on her, for example, *family practices* that had been interrupted, such as days out and holidays, which were no longer felt possible. Regrettably, it was aspects of family display that had prompted this because of what onlookers might think:

‘We always used to go out for the day, go on walks, pub lunches, it was our favourite thing to do.... I stopped just me and him, not because I couldn’t handle his actions and things, but other people looked at me like “you’re horrible talking to him like that”.’

Dementia disrupted their ways of relating to one another, and Evie experienced her previously loving parent becoming angry towards her:

‘The paranoia was directed towards me ... he’d say, “you’ve stolen my TV remote”, it was stupid, he was obsessed with it. I’d be like “no Dad, I haven’t, I haven’t touched it”, “yes you have”.... I was like, “no I haven’t” ... he’d just blame me for ridiculous things ... “you’ve taken my car keys”, “why would I take your car keys?” “You have.” And then I’d find them down the back of the sofa, which was the worse thing, and I’d go “found ‘em”, he’d go “see, told you”.... He’d call me names.’

Her father’s violence towards her led to him entering full-time residential care:

‘He grabbed my arm ... he twisted it and I knew it wasn’t really him ... it didn’t hurt me, but the way he did it. He wasn’t letting go ... something had changed ... I blamed myself completely ... if I’d not said anything about him hurting me ... but he had to go in. I still hate it.’

These excerpts demonstrate the fundamental changes to Evie’s relationship with her father, emotionally and physically as a result of his illness: he behaved differently towards her and the things they did together changed. And yet, the narrative reveals the means by which she maintains a father–daughter relationship via practices and performance.

## *Continuities*

Evie’s father’s rarely recognised her, nor was he able to converse ‘normally’. Despite this, she still *felt* his behaviours conveyed a sense of family; Evie interprets his smile as a display of familiarity:

‘He can’t really speak, I mean, he can but doesn’t make any sense and he doesn’t know me or Mum ... in a way he does because we get smiles but if you said “who am I?”, he wouldn’t, not anymore.’

For Evie, then, a smile has meaning that might be taken for granted were it not for the dementia.

Maintaining a relationship once her father entered care was a priority, and Evie describes what she did to enable this as follows:

'I left school because it would have been full time. No time allowed off.... I need time to see my Dad.... I'm not gonna only go at four o'clock at night when he'll probably be asleep. I was like "I need some allowance for that." [The headteacher said] "No". So I went for the distance learning option because I didn't want to feel that I was just leaving Dad.... I would rather put my family first even though it would be great to be with all my friends at sixth form.... As long as I can keep a relationship up with my Dad, you know?'

Evie felt that the onus to continue the relationship was on her, and she achieved this by continuing her family's normal practices. One example of this is through gift giving (Smart, 2007):

'I still try and keep presents and things nice.... I did buy a present from him to Mum and it wasn't half funny because it was a necklace with two hearts intertwined and I gave it to Dad and I said "you give it to Joanne" – because if I say Mum, it confuses him – he starts looking through this box ... "is there any chocolate?" I'm like "no".'

Evie identified occasions when her father participated in the father–daughter relationship, albeit in a temporally incorrect manner. She described an incident when a visual hallucination – common in dementia – caused him to perceive her as a child in danger:

'Carpet to wood ... he sees it as a drop.... There was one time a couple of weeks ago, I walked over and he was going "No! Stop Evie!" I looked at him and I thought "Oh, he said my name" and it's the one time he did but then I thought he's said it out of panic and I think he thinks of me as a young child.... I see him sometimes and he'll go "Evie, come here" as if I'm a little toddler. And I think the odd time he did recognise me, he said really strange things, like "oh let me do your hair" and I think he just looks back.'

While family talk is a simple, under-theorised aspect of family life, Evie's experiences of her father's dementia illustrates its significance. Evie finds visiting her father difficult because of the lack of conversation. She struggles with how to 'be' family without conversation, showing the importance of display in this situation:

'I just don't really know what to say a lot of the time ... before, I could have a good conversation with Dad, but now there's no conversation, he's normally just asleep, I don't know what to do. The whole visit, I'm just sat there thinking "okaaay".'

There is also the added complication that when he *does* speak, he is not necessarily going to be pleasant:

‘I just get so stressed out ... some of the things, sometimes he’ll turn round and say something hurtful and it’s really difficult to tell yourself that it’s not him.’

The relocation of her father to a care home alleviated some of the difficulties, so while it interrupted traditional conceptualisations of family that emphasise the importance of co-location, she felt it improved the relationship: “he’s less agitated towards me now.” Co-location is not vital to their emotional connection: the relationship transcends where they live. She thinks of him at night and worries about him:

‘I think I suffer a lot from I can’t sleep at night because Dad can’t sleep ... he just walks and I think that, I get image of him walking around all the time.... When he couldn’t sleep when he was at home, I would sit up with him and talk to him but obviously with him there, I can’t.’

Evie’s account suggests that dementia can lead to improvements in some family relationships – albeit at a considerable price.

‘It has brought me and my Mum closer together, I mean, we are super close now: that is a good thing.’

### *Reconceptualising relationships*

It has been suggested that family is what family *do* (Morgan, 2011). Evie’s account revealed the ways in which her father–daughter relationship had been reconceptualised by herself and others. She recalled an incident when she was 14 where she had tried to curtail her father’s spending. Perceiving her father as incapable of making a decision regarding a contract for a satellite television and broadband package, she attempted to stop him. We return to the display element of families, notably other’s perceptions:

‘We went to the supermarket and he saw this Sky Broadband stand with a man stood on it and he went over and went “yeah yeah, I’ll take one out with you” and I was like “no Dad, you don’t want to do that”.’

To those who did not know him, her father appeared capable of making decisions even though he wasn’t, while Evie felt that she was perceived as unable to make decisions, even though she was.

Neither Evie nor her father are meeting the expectations of other people, in this instance, the salesperson:

‘I was 14 at the time, so this man is looking at me like “what are you doing” and at that point, I just had to leave it because I just looked so bad just having a go at my Dad when he’s going, “yeah yeah”. So Mum had to go and cancel it all.’

This example shows how family practices have changed in the face of dementia and Evie’s efforts to perform them.

## Austin

Eight-year-old Austin's family included his father who has frontotemporal dementia, his mother and his older sister and brother (from his mother's previous marriage). Austin's father rarely speaks and finds routine tasks such as cutting up food and using stairs difficult. At the time of the first interview, Austin's father was living at home, although he subsequently moved into residential care.

### *Disruption*

Austin's story of his father's condition immediately places him at the centre when, aged four, he received some Lego for Christmas. At that time, the doctor had diagnosed his father's memory problems as stress-related, although this wasn't perceived as being serious or significant. However, the simple practice of a father playing with his son did come to be recognised as an epiphanic moment in the family's growing recognition that something was wrong. His father was unable to construct Lego designed for a four-year-old:

'... he bought me a Lego set and he couldn't do them.... I would sit with him and he would pick up the wrong pieces and didn't know what to do and he just kept on sighing, saying "I just can't do it".'

Indeed, Christmas is an important family practice (Mason and Muir, 2013), with gift giving part of family life (Smart, 2007). However, these practices were disrupted by dementia.

As for Evie, Austin also found that his father's condition meant that normal activities and means of family display such as a day trip were not possible as this parent was no longer able to be in sole charge of his child:

'We used to go out all the time but then we couldn't because he didn't know what he was doing anymore ... we used to go on the train but then sometimes he might have got the wrong ticket and when it got worse, Mum said we had to stop going out because he might get the wrong ticket and get on the wrong train ... we always used to go to Birmingham, go to the Bullring, go to The Entertainer, go to Burger King, and just come back. But it got worse and Dad couldn't go out on his own anymore.'

Again, in common with Evie, on a day-to-day basis, basic interactions are challenged by dementia. He, too, cannot participate in a chat with his father:

'We can't get conversation out of Dad at all because he just sits there and watches TV, just sits there and never talks.... I just have to keep reminding myself he can't remember what to do and stuff.'

This child cannot expect to have a conversation or play with his father, and yet he may be called upon to help him with tasks such as cutting up food:

‘The other day, he couldn’t even cut up his toast because I’m not sure if he couldn’t see ... he put the fork in the bread but was trying to cut it with his spoon. He was cutting it here but then his knife was there so we weren’t sure if he couldn’t see it.’

Previous research suggests that mealtimes are an important example of family practice and display (Smart, 2007; Curtis et al, 2010), such as preparing and eating meals together. Therefore food practices remain significant here, albeit in a manner that is essentially non-normative.

Maintaining a relationship with your father when you are eight and cannot converse with him or depend on him to do the things he used to do requires work.

### *Continuities*

During the discussion, Austin cited watching TV as one of his hobbies:

‘My favourite show on TV is “Friends”. I sit and watch that with Dad.’

Watching TV is a part of life that Austin’s father still enjoyed, and it facilitated their relationship. This is an activity that most families take for granted but which acquires privileged meaning for Austin. Football was another favourite pastime – playing it, watching it or visiting grounds – and it had been an important component in his relationship with his father, for example, he mentioned his dad taking him to Old Trafford (Manchester United’s football ground) before he became ill. However, football as a way of ‘doing’ family had been challenged by dementia, with his father no longer able to watch his football matches.

M: ‘Who watches you play?’

A: ‘My Mum.... Dad goes to Grandma’s mainly. Before he used to come. He always used to enjoy talking about it to me, like how well I’d done, but now he has to go down Grandma’s when I play football.’

M: ‘How does that make you feel?’

A: ‘It bothers me a bit.’

Upon visiting Austin a second time, he had received a football goal for the garden as a birthday present. This unexpectedly allowed football to re-enter the frame as a shared activity.

M: ‘Who do you play with?’

A: ‘Dad ... he goes in goal and I kick the ball.’

M: ‘When did you last play with Dad?’

A: ‘A couple of days ago.’

M: ‘And do you ask him to play?’

A: ‘No he just does it out of the blue, he wanders over to the pitch. At first he just went to the pitch and so I went to play with him.’

M: 'Do you like it when that happens?'

A: 'Yeah.'

Austin's story demonstrates how the ordinary aspects of child–parent relationships are interrupted in the face of dementia, yet it is also the ordinary practices and display that offer continuity, as the football example shows. Whereas *watching* his child play football had displayed the relationship between parent and child, this had disappeared, yet the example of playing football together shows how displays are perpetuated.

### *Reconceptualisation*

Dementia adds a dimension to the relationship that is far from normal for an eight-year-old. For example, Austin has to help his father downstairs and he, poignantly, incorporates helping his father into his own future:

'The other week or so, I had to help him get down the stairs because he just didn't know which foot to put where.... When I'm older before I get a job I will try and help out a bit more like taking him places and stuff. At the moment I'm too young.'

Austin's account reveals that he has considered his father's needs, and suggests that he has reconceptualised their relationship – that it is he who must help his father rather than vice versa. For Austin, play continues to be a mediator, although he must wait for his parent to instigate play with him, instead of pestering him as other children might.

### **Lauren**

Lauren, 24, is an only child whose parents divorced two years ago. In retrospect, she believed her mother's dementia-related behaviours contributed to the split. Her family live in the South West, while she moved to London prior to her mother's definitive diagnosis.

### *Disruption*

Lauren cited a series of unusual behaviours that, with hindsight, she now relates to the dementia. Like Austin, Lauren's story incorporates a Christmas anecdote. Aged 22, with a lifetime of Christmas traditions behind her, Lauren is shocked that her mother appeared to have forgotten that it was, in fact, Christmas:

'We got the tree up, and it was okay until I woke up on Christmas morning and I didn't have a stocking which I was a bit kind of put out but I was also thinking "I'm 22 now maybe I don't have stockings." And then I was like "where are the presents?".... It was, like, really strange ... I was getting a bit upset about it and then I said "Mum, you know, you do realise what day it is today?" and she was like "oh, it's what's it called, Chris – it's Christmas isn't it?" and I said "well, there aren't any presents" and she was like "yes there are" and I was "well, they are not under the tree" and she was like "I must have put them somewhere." And then went into her wardrobe and then found

that they were there ... it was sort of quite an awkward moment, I didn't really know how to react to it ... that was quite a turning point.'

Again, well-established ways of being and displaying family are disrupted. As with Evie and Austin, everyday family routines were called into question. Lauren recalled how her mother's cooking and shopping habits altered, and that this was another occasion when she felt something was amiss:

'When I moved back home [after university], we'd buy really cheap £3 lasagnes and we'd always had fresh food, and suddenly she was like "this is much easier and it tastes delicious and it's only £3" ... and we had the same thing every night, I just thought maybe she's being assertive, maybe she was like "I don't want to cook so you can have what's put in front of you sort of thing" ... and just sort of thinking, okay, we'll eat it, but you're kind of looking at each other and thinking, this is really strange ... looking back, there's lots of things.'

Again, food practices as ways of doing and displaying family are problematic (Smart, 2007). Changes in eating habits that might not appear significant at first sight – after all, Lauren is being cooked for and is of an age when she could be expected to cook for herself – are known not to be normal practice for *her family*. The same ready meals, night after night, are not what the family did in the past. Disruption has occurred. This illustrates expectations about what family members do for one another, and the rupture dementia causes.

### *Continuities*

The onset of dementia presented Lauren with ways of 'doing' family, but they were largely shaped by her mother's health needs, in particular, taking control of her finances because she became prone to overspending as a result of her dementia. Lauren's mother was keen to continue the family practice of gift giving (Smart, 2007), but this was at odds with her competence to manage her finances, and thus Lauren was forced to intervene:

'A lot of [gifts] I went and returned it... She'd been buying things for, like, children ... we don't have any children ... she'd bought £70 worth of stuff here, it was random ... so I took her card away from her.'

Lauren's daily routine included phoning her mother each day when she was on her way to work, demonstrating that family need not be co-located (Morgan, 2011):

'The tube is, like, a five-minute walk, I will call her as I get out of the door, call her, you know, "hi Mum what are you doing today, remember you have your class, are you up and dressed?" "Yes." And I used to not call her that early because I didn't think she got up that early, but now I think she normally, she's normally awake by seven, and will get up ... some of the calls we have are a minute long, but that's all she needs.'

Regular contact was one of the ways of perpetuating the relationship, although Lauren also felt that formal care arrangements would have the potential to improve it so that it wasn't dominated by dementia. This suggests that quality time is important to young adults like Lauren.

'In a home ... it would probably make my relationship easier rather than in the morning.... I always have to call her to orientate her because of the times I've forgotten to do that, she's wandered out ... if I have time off [to visit], I have to try and get everything in one day.... Financial adviser won't see her without me and I have to see him in the week ... if she were in a home, I'd be able to go down, take her out for a coffee, spend time, *good* time with her ... whereas at the moment, "what do we need to do? We need to get you new socks, need to get you new shoes." It's a very busy kind of time.... I wouldn't be able to go back and see my friends at the same time, it's very very busy ... trying to get everything done, and then when I come back, I feel like I haven't done half the stuff.'

By the follow-up interview, live-in carers had been brought in, which Lauren felt had helped their relationship. She was able to spend more 'quality' time with her mother, although some renegotiating of the relationship was required, for example, as she described:

'Like what I would do if I had a granny which is we go out for a cup of tea, sometimes I take her out for a meal in the evening but she can't really drink. I can give her say like a cider or something but not too much, not wine, and so what I call "granny things". Coffee and cake is good because it doesn't require much effort on the mind for her. Maybe like a little walk, try and tire her out a bit so that she can have a little nap.'

By the same token, the time they spent together wasn't entirely for Lauren's enjoyment, indicating another example of family display – that Lauren spends time with her mother to *perform* the mother–daughter relationship:

- M: 'Would you say you enjoyed spending time with her?'
- L: 'It's okay. Obviously I enjoy it because she's my Mum but it's not like "oh let's go shopping or get our nails done".... I normally try and do practical stuff like clothes shopping with her because her size changes all the time and I'm probably the only one who gets away with saying "right you're having this." Otherwise it's very "I don't want this, I don't like it." She used to be like that before and I just thought, "oh she's moaning" ... when I was say the age of 16, we used to do a lot of mother–daughter stuff, shopping, go to London for the day. I valued her opinion on clothes but then it started getting, "oh this is rubbish" and I was like "everyone has this and I want this".... I can't remember the last time I really enjoyed it because Mum was different.'



Some of the time that Lauren spent with her mother was for her own benefit, but there was a temporal aspect to this, insofar as Lauren was spending time with her in the present for the benefit of her future self:

‘Mum is older than other mums and I do look at her and think actually she’s old. She’s 67 this year, and I don’t know how long she’ll live ... say if she went tomorrow, I’d feel good that I’d seen her and spoken to her quite recently.’

In Lauren’s case, the continuities such as taking control of her mother’s finances and seeing to some of her mother’s practical needs point towards the shift in their relationship. Indeed, Lauren explicitly states that she has come to regard her mother in a different light. This might be expected at some point between the parent and child, but at a later stage in the life course, and even then, it can be difficult to tolerate (Ward-Griffin et al, 2007).

### *Reconceptualising*

Lauren’s narrative references viewing her mother in a different light. She has described viewing her in a ‘granny way’, doing ‘granny things’. Throughout her interview, she stated that she had ceased to see her mother as a parent figure but that, in her eyes, her mother had taken on a child role. Either way, she constructs her mother as the *cared-for* rather than the *carer*. This reiterates the interruption to the parent–child relationship at this premature stage.

### **Discussion and conclusion**

Morgan’s framework emphasises the ‘active construction of family life in everyday, diverse family contexts’ (cited in Ellis, 2013, p 255). Finch’s ‘family display’ work points towards the everyday things families do with and toward each other to produce family. Our data illustrates how YOD causes significant disruption to existing practices and displays, and how new ones developed in response can help perpetuate family. Previous research has explored family practices in families in ‘crisis’, and this data adds new perspectives to the field. Caring is an everyday practice for some children and young people, and the data presented here consolidates this view. Indeed, so taken-for-granted are these practices performed as a result of dementia, that children and young people do not see themselves as carers, even though it might be clear to outsiders. Svanberg and Stott (2010), for example, reported that participants did not feel they had sufficient responsibilities to warrant this label, and participants in this study corroborate this view.

There are also characteristics of parental dementia that warrant specific attention, rather than being subsumed into the literature on young people’s experiences of parental illness and caring. For example, there are fundamental personality changes and behaviours directly attributed to the illness, rather than the experience of being ill. There are the lost functions and also lost memories (Smart, 2007). Dementia fundamentally affects the ways in which family is performed as the continuities and reconceptualisation of family practices and display illustrate.

Crucially, the nature of the disease has an ongoing downward trajectory. Without denying the impact of illnesses such as cancer and mental illness, dementia *is* a terminal

illness without a potential cure, a fact that is overlooked in a society that sees dementia as memory loss in older people (Sikes and Hall, 2016). These young people are in a process of constant change and adaptation with uncertainty about the timeline and rate of change. This demonstrates the case for a construction of family that captures fluidity over time, rather than a fixed definition (Morgan, 2011). Although fluidity of family roles and health identities is not in doubt, academically speaking, there are key challenges to having a parent with YOD. It comes at a premature stage of the life course for both parents and children, and is sudden and difficult, but services are not geared to help (NCB, 2016). Despite the clear impacts on parent–child relationships, narratives revealed that support for the family was scant. Participants relied on the well parent or siblings, to a degree, although not all young people have these. It is also worth noting that while all our participants exhibited their work in maintaining family, not all will, or will do so all the time. For Keady and Nolan (2003), the quality of care that people receive and the nature of continuing relationships in dementia is contingent on family relationships prior to the diagnosis. Not all young people will have grown up in a harmonious idyll, potentially having difficult relationships long before the onset of illness.

Concurrent to this is the fact that whereas other illnesses may benefit from 'scripts' (Sikes and Hall, 2016) to draw on in difficult situations, this is not the case for YOD. People do not necessarily recognise that dementia affects younger people. We are reminded of Sontag's *Illness as metaphor* (1979) that highlighted the stigma associated with cancer in the 1960s, which has arguably waned, and the same again for HIV/AIDS. This remains the case for dementia.

Focusing on family practices allows for a fuller understanding of the maintenance of relationships when an illness like dementia erodes the very essence of a family member. Dementia leads children and young people to actively participate in new practices and displays, while denying them previous forms. These young people's accounts convey the meaningful nature of the taken-for-granted, and the scale of what has been lost. There are different doings of family and these narratives of 'before' and 'after' highlight the profound changes that have occurred. Parental dementia also questions our understanding of what it is to be a child or young person: for example, that children should not have to deal with memory problems, incontinence, acting as a Power of Attorney or making decisions about care. It is clear that parental dementia amounts to significant losses, and warrants greater support.

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<sup>1</sup> Corresponding author.

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